Introduction

Diagnosis of multiple sclerosis (MS) is life changing for patients. The impact of diagnosis may be particularly pronounced for those diagnosed at a younger age (<30 years). This diagnosis and the journey of managing the disease in progressive or relapsing-remitting patients, and the use of new treatment modalities, necessitate patient education and support. We explored understanding of MS diagnosis, progression and disease classification from the patient’s perspective to help improve understanding of MS.

Methods

In-depth qualitative interviews with 11 patients diagnosed with MS as adults and 1 adult diagnostically diagnosed with MS as a child were conducted. Of the adult patients, 10 were female, 7 were Caucasian (5 RRMS, 3 SPMS), 2 were Black (1 RRMS, 1 SPMS), and 4 were Hispanic (3 RRMS, 1 SPMS). Interviews were conducted in person (3 patients) or over the phone (8 patients) and lasted 1-3 hours. Interviews were transcribed and analyzed using the framework approach to qualitative research.

Results

MS diagnosis

• There is growing recognition of the need to understand patients’ perspectives on MS

• An MS diagnosis can elicit feelings of shock, anger, or even relief. Such emotions may be helpful in understanding of MS

MS progression

• Clinical classification is important for understanding the disease trajectory

MS phenotypes

• In 2013, MS was classified into distinct phenotypes, with sub-classification for disease activity and progression (Table 1) (Kantar D, Miller KM, et al. Neurol Ther 2017; 6: 57-72)

Table 1: Suggested Phenotypes for RRMS and progressive MS

<table>
<thead>
<tr>
<th>Phenotype</th>
<th>Description</th>
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<tr>
<td>RRMS</td>
<td>Relapsing-remitting MS, characterized by clinical relapses and remissions.</td>
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<tr>
<td>SPMS</td>
<td>Secondary progressive MS, characterized by progressive accumulation of disability without relapses.</td>
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<tr>
<td>primary progressive MS (PPMS)</td>
<td>Progressive accumulation of disability without relapses.</td>
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<tr>
<td>progressive-relapsing MS (PRMS)</td>
<td>Progressive accumulation of disability after relapsing course.</td>
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MS classification

• For patients, it may be appropriate to describe MS as part of a disease spectrum

MS management

• Different people have different needs and expectations of their MS treatment

MS care

• For patients, it may be appropriate to describe MS as part of a disease spectrum

Conclusions

• Although results help guide neurologists diagnose MS, patients experience lifelong changes before being diagnosed and managing treatment

• Patients may experience impinging on wholeness when diagnosed with MS. The experience of diagnosis parallels those with cancer.

• For patients, it may be appropriate to describe MS as part of a disease spectrum

References


